PERSONAL CARE ASSISTANCE

WORKGROUP REPORT

February 20, 1996

THE COMMONWEALTH OF MASSACHUSETTS

MASSACHUSETTS DEVELOPMENTAL DISABILITIES COUNCIL

PERSONAL CARE ASSISTANCE

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The PCA Workgroup was convened by the Massachusetts Office of Dispute Resolution through a grant funded by the Administering Agency for Developmental Disabilities

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EXECUTIVE SUMMARY

Between April and November 1995, the Massachusetts Developmental Disabilities Council (MDDC) sponsored a group facilitation process for consumers, advocates, state agency representatives and parents to develop recommendations to improve the Commonwealth's Personal Care Assistance (PCA) programs. The Massachusetts Office of Dispute Resolution and Mr. Jamie Katz, Esq., were engaged by the MDDC to form the PCA Workgroup, and to facilitate the group process. The role of the facilitators was to ensure that the final report represented a consensus of opinion among the Workgroup participants. The Workgroup met at regular intervals to discuss the strengths and weaknesses of the existing Massachusetts PCA programs, and to identify goals, funding options and solutions to problems facing the PCA programs.

This report contains three sections. The first section, written by Attorney Jamie Katz, summarizes the activities of the PCA Workgroup. In addition to identifying the major issues and concerns regarding PCA programs, this report provides the reader with an overview of the group process, a discussion of the groups' support of consumer control of the personal care attendant services, their concern regarding the underserved and unserved populations, and the potential financial impact to the PCA programs if and when Medicaid funding devolves to the states.

The consensus recommendations of the PCA Workgroup include:

- To establish a PCA advisory committee, comprised of consumers, agency representatives, providers and advocates, to advise EOHHS on the steps need to implement the recommendation of the work group.
- To define the PCA as an employee and to establish a PCA pay rate that includes compensation for employment insurances. Those insurances must include Social Security Benefits (FICA) and Worker's Compensation Insurance.
- To ensure that consumer control remains the hallmark of PCA services.
- That PCA services are accessible to all who need them.
- That current funding sources be examined to maximize the accessibly of PCA services to persons with disabilities.

The second section contains the Employment subcommittee report on PCA tax and wage issues. The subcommittees' main focus of concern centers on the definition of "employer" for the Personal Care Assistant. Currently, there is no consensus among providers of PCA services, consumers and state agencies as to who is the PCAs' employer. However, Internal Revenue Service (IRS) rulings and recent reports by national experts suggest that the PCA is not an independent contractor, and that the employer is the consumer of PCA

services. Thus the individual consumer is responsible for all employment related benefits and liabilities. The subcommittee report also contains a review of employment, tax and liability issues and reviews the options for a rate increase for PCA services.

The conclusions and recommendations of the Employment Subcommittee include:

- That a PCA, consistent with IRS employment standards, is an employee, not an independent contractor or consultant, and is entitled to employee benefits.
- That it is unclear whether the state, vendor or consumer should be designated as the employer.
- The issue of who is the employer must be clearly defined and uniformly implemented in Massachusetts.
- To implement a State-wide Personal Care Assistant program that incorporates Worker's Compensation, Unemployment Insurance, and consistent administrative guidelines, an increase in the PCA hourly rate must be implemented.

The third section contains a report written by the Human Services Research Institute (HSRI) titled "A Baseline Overview of PCA Services, Underserved Population, and Program Costs". This report, funded by the MDDC at the request of the PCA Workgroup, provides a discussion of PCA policy, program costs (labor), and identifies the number of persons who qualify for, but currently do not receive, PCA services in the Commonwealth. The unserved include children with disabilities living at home with their families, and individuals living in institutional settings who would otherwise qualify for PCA services in their own homes. It is important to note that this report was not accepted by the PCA Workgroup as a whole, as it was considered not to be useful to their deliberations (Page 11). However, the MDDC believes that the report provides useful information to the reader about unserved and underserved populations, and has chosen to include it as an Appendix to this report.

PERSONAL CARE ASSISTANCE

WORKGROUP REPORT

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REPORT OF THE PCA WORK GROUP

The Massachusetts Developmental Disabilities Council arranged and supported a series of facilitated meetings among interested parties concerning the funding and provision of Personal Care Attendant (PCA) services for individuals with disabilities, including children and the elderly. This report summarizes the work and recommendations of a group of representatives from state agencies, PCA providers, advocates, and consumers who have met on a regular basis since the spring of 1995.

Background

Last winter the Massachusetts Developmental Disabilities Council (DD Council) issued an RFP for facilitators to conduct a series of meetings among agency representatives, advocates, PCA providers and consumers. The focus of the facilitated meetings was to be the question of how to provide funding for PCA and PCA-like services for underserved and unserved populations. One of the most visible issues which was then of concern was the on-going debate about the interpretation of PCA eligibility regulations by the Division of Medical Assistance (Medicaid).

The facilitators selected to run the meetings were Jamie W. Katz, Esq. and Jane Wells of the Mass. Office of Dispute Resolution. The facilitators and the DD Council invited a wide variety of participants to the meetings, including the following:

State agency Representatives--

Division of Medical Assistance

Department of Mental Retardation

Department of Mental Health

Massachusetts Rehabilitation Commission

Executive Office of Elder Affairs

Massachusetts Commission for the Blind

Massachusetts Office on Disability

Massachusetts Developmental Disabilities Council

Massachusetts Office for Children

Providers, Advocates, and Consumers--

North Shore Arc

Massachusetts Arc

Northeast Independent Living Program

Independence Associates

Families Organizing for Change

Disability Law Center

Massachusetts Head Injury Association

Options/Cerebral Palsy of South Shore

Rosemary Larking (Consumer)

Stavros Center for Independent Living

In the meetings that followed, a core group of approximately twenty persons from the list of invitees regularly attended. Those participants were representative of the diverse interests represented among the invitees and included participants from each category of invited groups. Nine meetings were held between March 6, 1995 and

November 20, 1995. The group used a consensus-based approach to discussing and coming to resolutions.

Process

The group met at regular intervals to discuss PCA issues. Initially, members of the group identified the scope, range, and definitions of PCA services. The group discussed both the strengths and weaknesses of existing Massachusetts PCA programs and services. The group discussed goals which should be incorporated into PCA and PCA-like programs as well as different funding options and various solutions to the problems facing those programs.

The group sought to attain a common understanding of the underlying facts and circumstances relating to the various programs providing PCA and PCA-like services, as well as the need for those services. To that end, each state agency which provides PCA or PCA-like services conducted a presentation to the group to provide information on those services. In addition, in an effort to obtain information about the potential methods for structuring funding for PCA programs, the group received two presentations from Gary Smith, Director of Special Projects for the National Association of State Directors of Developmental Disabilities Services. Mr. Smith provided information about how other states handle the funding and the provision of PCA services, as well as the political situation in Washington, D.C. concerning the status of funding for health and human service programs. In addition, Kim Smith of the Rate Setting Commission made a presentation concerning the establishment of the rates for PCAs, including a discussion of the history of the rate and the factors involved in setting it. Commissioner Bruce Bullen of

the Division of Medical Assistance also made a presentation concerning the status of the proposed federal legislative and budget changes for Medicaid, and the implications for Massachusetts.

During the period in which the group was meeting, DMA and DMR entered into an Interagency Service Agreement with respect to PCA and PCA-like services performed for DMR consumers. This information gave the group some sense of possible mechanisms for dealing with the issue of improving and expanding the available PCA and PCA-like services.

A particular interest of concern to the participants was extending PCA and PCA-like services to unserved and underserved populations. The group was able to gather some data concerning the size of groups which were unserved or underserved, but the absence of critical data in certain areas was a deterrent to group decision-making. As a result, the group determined that data needed to be collected and analyzed to assist in the decision making process. The DD Council agreed to contract for a study which would collect and assess the pertinent data. The DD Council contracted with Human Services Research Institute to perform a study to gather and analyze information regarding unserved and underserved populations, along with the costs of providing PCA and PCA-like services.

The group also established a subcommittee to discuss related wage and tax issues of the PCA workforce. The subcommittee produced a separate report, which is included at the end of this summary.

External Forces

As the facilitated meetings progressed, it became clear that the focus of the group had to change. The enormous political changes in Washington, D.C. and, consequently, in the funding of health care and social service programs, had an enormous impact on the goals of the group. It became clear, for example, that funding will eventually devolve to the states in the form of block-granting. Further, federal funding will diminish, if not immediately, definitely over a short period of time. The issue of the interpretation of the existing Medicaid regulations thus became less of a priority in light of the overall uncertainty of long-term funding for PCA and PCA-like services. As the budgetary and legislative changes evolved, and the future (both immediate and long-term) environment became less certain, it became more difficult for the group to make definitive, specific recommendations as to funding or structuring of PCA and PCA-like services.

RECOMMENDATIONS

A. Goals

The PCA group first developed consensus on the following recommended goals:

1) In any funding model which continues or develops, the most important characteristic of the Massachusetts PCA model is that consumers have control over the services, and the group recommends that consumer control be maintained;

2) Expand PCA and PCA-like services to unserved or underserved populations with a broad view of the services provided;

3) Ensure the workforce is of high quality, and clarify the status of PCA consumers as employers;
4) Review the PCA hourly rate in recognition of the status of PCA as employees. Issues including FICA taxes, unemployment, and workers compensation should be taken into account.
5) Create and support an on-going, working Advisory Group at the Executive Office level to provide a forum for exchanging information and providing advice concerning PCA and PCA-like services; and
6) Make more coordinated and efficient use of fiscal, programmatic, and other resources which are used to provide PCA and PCA-like services.

B. HSRI Report

The PCA group received a draft report from HSRI. After careful review of its contents and considerable discussion, the group determined that it could not rely on the draft report, nor was it useful to its deliberations. Therefore the PCA group did not accept the draft report.

C. Advisory Group

As indicated above, the group recommends the formation of a PCA Advisory Group. The PCA Advisory Group should look at the broad continuum of community-based services for individuals with disabilities and consider better coordination of PCA and PCA-like services. The PCA Advisory Group should be placed to advise the Secretary of

the Executive Office of Health and Human Services and the Commissioner of the Division of Medical Assistance.

The Advisory Group should exchange information and recommendations. It should serve as a forum for the discussion of issues and for input on an advance notice of new policies and proposals with respect to PCA programs. The PCA Advisory Group does not need to have approval authority but must be designed to facilitate the exchange of ideas and data, and have a direct link to policymakers.

Analogs for the PCA Advisory Group include the Governor's Interagency Coordinating Council, the Special Needs Housing Taskfroce, Statewide DMA Advisory Council, the Facility Consolidation Group, and the Governor's Disability Policy Group. The PCA Advisory Group should include the following representatives:

Consumers.

Personal Care Attendants.

State agencies—Department of Mental Retardation, Division of Medical Assistance, Massachusetts Rehabilitation Commission, Department of Mental Health, Massachusetts Commission for the Blind, Executive Office of Elder Affairs, Massachusetts Office on Disability, Massachusetts Developmental Disabilities Council, Massachusetts Commission for the Deaf and Hard of Hearing, and the Department of Public Health.

Providers—Independent living centers, home health agencies, private insurers, PCA providers, surrogates, and case managers.

Members of other advisory committees not identified here could also participate as representatives to the PCA Advisory Group.

A majority of the composition of the PAC Advisory Group should consist of consumers, either by numbers of participants or by votes, so there is consumer control of the Advisory Group. The consumers should also be, in the main, independent representatives not employed by or representing PCA programs.

The PCA Advisory Group should have a staff base for support and a funding stream.

D. Next Steps

The group recommends that this report be submitted to the newly-created Advisory Group as a starting point for continued discussion. The group also recommends that the interested parties and agencies work to clarify the status of Personal Care Attendants as employees, and to deal with the attendant employment law, tax, and liability insurance issues.

Preservation of consumer control is critical. Massachusetts might look to California or other state models in which a state agency provides payroll and tax services while the consumer retains control. Private payroll services are also possible.

The group recommends that there be flexibility as to fiscal intermediates (i.e., independent living centers, co-ops, individual PAC users, or a menu) between Personal Care Attendants and their employers, so that consumers have appropriate models for ensuring both that consumer control is maintained and the employment status of Personal Care Attendants is clarified.

PERSONAL CARE ASSISTANT

EMPLOYMENT SUBCOMMITTEE REPORT

ON TAX AND WAGE ISSUES

SUBCOMMITTEE MEMBERS:

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Special thanks to Louann Larson and Ann Shor for their written contributions.

INTRODUCTION

Personal Care Assistance has long been hailed by advocates in the disability field as a community support characterized by user control. The individual receiving services is essentially in charge of developing the Personal Care Attendant's (PCA) job description, as well as hiring, training, paying, and if need be, firing the PCA. However, control is also the feature of the service that is the most obscure when debating the issues of federal and state wage taxation, and related insurance. On the surface, the notion that the consumer of PCA services is in control of the employee suggests that the consumer is the employer. Thus, the consumer would assume the legal and tax obligations that are a part of the designation ''employer''. The Employment Subcommittee on Taxes and Wages was formed as a subgroup of the PCA Workgroup to address this issue.

THE PROBLEM

A significant number of Massachusetts PCA consumers have expressed concern that in addition to the challenges they already face in their daily lives, the implications of employer liabilities push them beyond the reach of their financial and/or managerial capabilities. Further, the hourly rate of pay authorized by the Commonwealth for an individual PCA is insufficient to cover the additional costs for worker accident and disability insurance (Worker's Compensation Insurance); Social Security and Medicare (FICA) and Unemployment Insurance.

For sometime, it was expedient for state government and service providers not to address the employment issues. For example: Who is responsible for tax reporting? (Potentially there are eleven different forms to be submitted by the consumer and the PCA) Where should the funds come from to pay the employee contributions for FICA, Unemployment Insurance and Worker's Compensation? What entity (the state, the vendor or the individual receiving PCA services) is liable in the event that a PCA is injured while working? Neither state officials or advocates were eager to draw attention to these fundamental problems for fear that attempts to "legitimize" the service would produce something too costly or too administratively burdensome to remain viable.

Vendors across the state have struggled with these employment issues and developed guidelines and skills training curriculum to address them. With regard to taxes, some vendors indicated that they advise people to simply pay the PCA and not assume any tax reporting responsibilities. Others advise consumers to treat their PCAs as private contractors or consultants and file 1099's on a yearly basis. At least one agency indicated that it submits 1099's on all payments made to consumers, thereby requiring consumers to submit 1099's on all wages paid to their PCAs. Another vendor advises consumers that according to the Internal Revenue Service (IRS), they are the employer and should contact the IRS or an accountant for tax advice.

The lack of clarity about PCA employment tax and insurance liability reflects a general ambivalent attitude toward consumer control and personal assistance. On one hand, Department of Medical Assistance (DMA) officials have indicated concern that the PCA program is relatively unregulated and unmonitored, and therefore subject to abuse. On

the other hand, there is recognition of the inherent efficiencies of a service that cuts out the "agent" and delivers support services directly to the consumer, on location. In order to fully understand the issues relevant to the implementation of the PCA programs, the interests of three groups need to be recognized.

First, the Consumer can not be burdened by additional out of pocket costs for PCA services and paperwork, and should be reasonably protected from liability.

Second, the PCA is entitled to a decent net wage and must have reasonable and appropriate protection in case of employment related injury or loss of employment.

Third, The Commonwealth must provide necessary supports to persons with disabilities at the lowest possible costs; must ensure that services are provided within the framework of state and federal laws and regulations; and must ensure that all citizens are properly contributing to the tax base.

PCA EMPLOYMENT STATUS

There is a growing consensus among consumers, providers and advocates, as well as regulating agencies, that individuals working as PCAs, who are currently considered to be independent contractors, more closely meet the criteria for employees. When the IRS 20 item test of employee versus contractor status is used, clearly PCAs working conditions meet the majority of tests for regular employee status (Revenue Ruling 87-41, 1987-1 C.B. 296). According to Sabatino and Litvak, Revenue Ruling 87-41 provides that:

> " the relationship of employer and employee exists when the person or persons for whom the services are performed have the right to control and direct the individual who performs the services, not only as to the result to be accomplished by the work but also as to the details and means by which that result is accomplished. That is, an employee is subject to the will and control of the employer not only as to what shall be done but as to how it shall done. In this connection it is not necessary that the employer actually direct or control the manner in which the services are performed; it is sufficient if the employer has the right to do so." (p. 12)[1]

EMPLOYER STATUS

In order to address the question of "Who is the actual employer of a PCA ?", the Employment Sub-Committee contacted the Internal Revenue Service (regarding FICA),

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[1] Sabatino and Litvack, Liability Issues Affecting Consumer-Directed Personal Assistance Programs, 1995.

the Commonwealth's Industrial Accident Board (Worker's Compensation Insurance), the Rate Setting Commission (regarding the history of the PCA hourly rate), and the Department of Employment and Training (regarding unemployment insurance). In addition, the Employment Subcommittee reviewed two reports on the employment status of PCAs (Consumer Directed Attendant Services: How States Address Tax, Legal, and Quality Assurance Issues, by Susan Flanagan, SYSTEMETRICS, 1994, and Report and Recommendations on Liability Issues Affecting Consumer Directed Personal Assistance Services , The World Institute On Disability, American Bar Association, Commission on Legal Problems of the Elderly, 1994).

According to the IRS, the employer is typically defined as the entity that negotiates the contract, pays the bills, makes payment to the employee, and/or sets the rate of pay (directly or indirectly). There was no clear consensus among those questioned as to who the employer of the PCA is. State and federal agencies felt that the provider agency could and possibly should be the employer. Others, including providers and consumers, felt that the consumer could be the employer in that they may recruit, train, schedule, supervise, pay, and if necessary, fire the PCA. The lack of clarity around the issue of employer places PCAs, providers and consumers in the precarious position of having responsibility for the financial obligations associated with employment taxes and insurances, as well as in the ethical dilemma of defining who is accountable for the legal entitlements of the PCA workforce.

Other states use models of cash grants, agency providers, and fiscal intermediaries, depending on the wishes and abilities of the consumer. In these models, the consumer, the provider, or the state agency is clearly identified as the PCA employer.[2]

ADMINISTRATIVE REQUIREMENTS

The Status of PCAs as employee rather than independent contractors places certain administrative and reporting requirements on the employer. This section provides a description of the administrative requirements, an estimate of time required to carry them out, and associated costs for staff time. Time cost estimates are affected by the number of consumers and PCAs involved. It is recognized that some consumers would find it necessary to delegate administrative tasks to another individual or agency to perform, much as corporations do with payroll processing.

FICA is the most time consuming benefit to administer. Each employer must call the IRS to obtain a federal tax ID number, and keep individual records for all employees. Individuals may not use their social security number. The employer must withhold 7.65% of each employees' paycheck for FICA. By the 15th of each month, the employer must pay this amount, plus their 7.65% share to an account established at a bank for this purpose. The employer uses a special coupon to do this and makes payments payable to the bank.

Estimated time required for FICA administration: 1 hour per month

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[2] IBID.

The employer must file a quarterly Deposit Report, showing the amounts and dates of the withholdings and the monthly totals of payment.

Estimated time required for Quarterly Deposit Report: 1 hour per quarter

Each January the employer must calculate and file a W-2 for each employee.

Estimated time required per W-2: 2 hours per year

Each quarter the employer must file a payroll form with the Department of Employment and Training, indicating the total payroll paid for the quarter. Any amount in excess of $15,600 paid for an individual employee is deducted, and the remainder is multiplied by the employer's unemployment insurance rate to obtain the amount of payment required.

Estimated time required: 1 hour per quarter

Worker's Compensation is handled through private insurance carriers using an insurance agent. At the beginning of each year the employer pays a premium for the coverage for the year, which is based on the established rate of 4.49% times estimated payroll for the year. At the end of the year the employer files a form to verify the actual total of the payroll for the year, together with any additional payment that may be due if the payroll was underestimated.

Estimated time required: 1 hour per year

The employer is required to file quarterly earnings reports with the state that indicate the gross earnings of each PCA.

Estimated time required: 1 hour per quarter

Converting all time requirements into annual figures, administrative time is equal to 27 hours per year. If a consumer chose to contract out for administrative services at approximate $20 per hour, the cost to the consumer would be $540 per year or $45 per month.

CONCLUSIONS AND RECOMMENDATIONS

The information reviewed by the subcommittee led to the following conclusions:

1. That a PCA, consistent with IRS employment standards, is an employee, not an independent contractor or consultant, and is entitled to employee benefits.
2. That it is unclear whether the state, vendor or consumer should be designated as the employer.
3. The issue of who is the employer must be clearly defined and uniformly implemented in Massachusetts.

In order for PCAs to transition from contractor to employee status, additional costs for Workers' Compensation and Unemployment Insurance are necessary. As independent contractors, PCAs are required to pay the full cost of FICA out of their PCA income. As employees, PCAs will be required to have Unemployment and Workers' Compensation

Insurances. If the additional costs of employment are not covered by the employer, and are taken from the existing PCA pay rate, then a reduction in PCA net pay will make it more difficult to find and,retain competent PCAs in a competitive labor market

To implement a State-wide Personal Care Assistant program that incorporates Worker's Compensation, Unemployment Insurance, and consistent administrative guidelines, the Employment Subcommittee recommends an increase in the PCA hourly rate. The increase can be from the current $7.85 per hour to either $8.38 or $9.14 per hour, dependent upon which of the following options is implemented. These modest rate increases would be sufficient to cover Worker's Compensation and Unemployment Insurance. These rates do not include state and federal income taxes. The PCA will experience no loss in current net income due to a shift in their employment status.

Current PCA Pay Rate:

Current hourly wage	$ 7.85
(15.3% FICA payment)	$-1.20
Net pay before income taxes	$ 6.65

OPTION #1

Gross Pay to PCA	$ 7.20
Employee 7.65% FICA payment	$-0.55
NET pay before income taxes	$ 6.65

Additional Costs for benefits include:

FICA @ 7.65% of $7.20 =	$ 0.55
Unemployment Comp. Premium*	
@ 4.30% of $7.20 =	$ 0.31
Worker's Comp. Premium**	
@ 4.49% of $7.20 =	$ 0.32
Total Additional Costs	$ 1.18
Gross Pay to PCA	$ 7.20
New Hourly Rate	$ 8.38

OPTION #2

It was pointed out that FICA should be calculated at a lower rate than 15.30% because the higher FICA rate is based upon the PCA having independent contractor status. The price of FICA for an employee is 7.65% (the other 50% paid by the employer).

In addition, since the PCA rate has not been increased in over six (6) years, the following option incorporates an increase by covering the FICA costs in the base rate.

Current PCA Rate:			$7.85
FICA	7.65%	=	$0.60
UNEMPLOYMENT	4.30%	=	$0.34
WORKER'S COMP.	4.49%	=	$0.35
			$1.29
New Proposed PCA Rate			$9.14

* The Unemployment Compensation premium rate of 4.3% was obtained from a single provider. This rate may vary as it is based on the employer's history of unemployment claims. The more claims that are filed, the higher the rate. (This rate variability may have a side effect of discouraging consumers from terminating unwanted PCAs.)

**The Worker's Compensation rate of 4.49% is that paid for Massachusetts employees in class 8835, which covers "nursing, health care, or homemaker services in the homes of individual patients." The text of the Worker's Compensation Manual describes the classification further: "the Code 8835 risk, in addition to providing household services of a domestic nature to residents of a household who are physically limited in the amount of personal care they are able to provide themselves."

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Baseline Overview of PCA Services, Underserved Populations, and Program Costs

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December 14, 1995

Baseline Overview of PCA Services, Underserved Populations, and Program Costs

In August 1995, the Massachusetts Developmental Disabilities Council contracted with the Human Services Research Institute (HSRI) to gather and analyze data regarding the unserved and underserved populations and the costs of Personal Care Attendant (PCA) services in Massachusetts. The report that follows provides an introductory, baseline view of those un- or underserved by the PCA program and the program's costs.

The Division of Medical Assistance (Medicaid) Personal Care Attendant program is the perhaps the most well known PCA service in Massachusetts. However, the Massachusetts Rehabilitation Commission also operates a PCA program, and the Department of Mental Health and the Department of Mental Retardation provide and/or fund support services similar, in some ways, to the Medicaid PCA program. Each of these agencies supplied empirical and anecdotal data for inclusion in this report. Provider organizations also supplied empirical and anecdotal data that state agencies were unable to provide or that appeared to necessitate explanation or confirmation.

Methodology

The Massachusetts Developmental Disabilities Council (MDDC) supplied HSRI with the names and telephone numbers of members of the PCA Workgroup. HSRI drafted questionnaires (Appendix A) regarding Personal Care Attendant services and distributed them via mail and FAX. Additional sources of data were solicited from Workgroup members and were contacted by HSRI where appropriate.

Individuals responded to inquiries about PCA services in personal interviews, telephone interviews, mail, and FAX. Much of the data requested of individuals was not readily available. Several individuals in private organizations and state agencies expended considerable time reviewing program and individual records to compile data for this study (Appendix B). Notably, not all organizations maintain the same information in the same formats. Data that could be aggregated across organizations and agencies are presented here along with organization and agency specific data.

Additionally, when empirical data could not be located or compiled within the time constraints of this study, individuals were asked to provide estimates or anecdotal information. Estimates and anecdotal information are included here only where the reporter is considered to have adequate knowledge of the situation (e.g. administers the PCA program, or handles appeals) and where estimates are limited in scope. (For example, one provider identified a "small

handful" of PCA applicants challenged the allocation of hours as insufficient. The provider defined "small handful" as 2-3 individuals. As the range was small, and the total number of appeals small in relation to the total number of applications, the estimate is presumed to be reliable and to have face validity.)

Analyses

Demographics of PCA users

Provider organizations and state agencies vary widely in the demographics of the consumers they serve. For example, one provider reports 64% of its PCA users have labels of mental retardation or other cognitive limitations, yet a second provider reports that the majority of PCA users have physical disabilities. The Division of Medical Assistance reports the most common condition for all PCA users served through its program is neurological deficit (spinal cord injury, cerebral palsy, multiple sclerosis).

Further, PCA is available to individuals who meet eligibility requirements of Medicaid through the Division of Medical Assistance. In these circumstances, the individual may or may not have paid employment. Yet individuals are eligible for the PCA program administered through the Massachusetts Rehabilitation Commission only if they are working, and the costs of PCA services are shared between the MRC and the consumer. Such variations among individual and programmatic characteristics necessarily require different data tracking techniques and present challenges to generalizability.

Unserved and Underserved Populations

Some children with disabilities do receive DMA funded PCA services. However, for the most part, children are considered ineligible for PCA services even when they are Medicaid recipients. A 1992 DMA Policy Memorandum (Appendix C) notes that assistance with activities of daily living is unskilled and can be performed by a parent, guardian, or voluntary caregiver. The memorandum further interprets regulation as limiting the service to medical necessity and least costly alternative. Because DMA would not reimburse parents or other family caregivers for the assistance given to a minor child, DMA interprets the free care of the parent or caregiver as a less costly alternative to PCA. Although there are anecdotal reports of fewer denials of services to minor children, and the DMA reports that children are among the population of PCA users, by DMA policy, minor children who live with their families have very limited access to the PCA program.

The Department of Mental Retardation reports that it provides or pays for support similar to Personal Care Attendant services to 2,736 individuals in community based programs (Appendix D). This figure includes individuals with cognitive impairments considered in the severe to profound mental retardation range and individuals with moderate or mild mental retardation and

severe mobility impairments. Formal review processes have indicated that 1,200 individuals are inappropriately placed in Nursing Homes, and 1,900 individuals are inappropriately placed in State Schools (ICFs/MR). 925 individuals requesting DMR PCA-like services did not receive those services this year. By DMR estimates, individuals who reside with their families comprise the largest singular group needing, but not receiving, PCA services. Approximately 2000 individuals have been identified in this group.

Generally, direct support staff provide instrumental and direct care to DMR consumers on a regularly scheduled basis through the Department or a private provider agency. Notably, DMR estimates that very few of its consumers can self-direct the PCA supports and must rely on a surrogate. As the paradigm for assisting individuals with mental retardation shifts from a service (program centered) model to a support (individual centered)model, PCA and PCA-like supports offer an appealing alternative. PCA and PCA-like services afford the individual care and assistance without necessitating the provision of assistance in a specified environment, like a group home. Essentially, models that replicate PCA release the state from the financial burden of providing service with housing. That is, a support model, where the provider (the personal care attendant) comes to the individual relieves the state of the capital and overhead costs of service models where the consumer must come to the service (e.g. nursing home, group home, vocational training center). Further, PCAs whether directed by the individual or by her surrogate unmistakably work for the individual. The field of mental retardation supports continues to struggle with the issues of how to assist individuals without treading upon their rights to autonomy and personal empowerment.

The Executive Office of Elder Affairs supports approximately 35,000 individuals through its home care division. Under present regulations individuals are determined eligible or ineligible for EOEA services, and therefore no waiting list is maintained. The EOEA is unable to estimate unmet need. Additionally, like the DMA, the EOEA does not rely on calculations of average number of service hours because of the diversity of consumer characteristics, need, and services. Initial conversations indicate that PCA, especially when determined and controlled by the individual requiring assistance, is an attractive model of providing support to the disabled elderly.

The Department of Mental Health was unable to separate out PCA-like services from the host of supports and services it provides. In response to this study, the Department of Mental Health (DMH) convened a focus group to examine the personal care attendant services consumers receive and to discuss how well the DMA model of PCA integrates with this agency's goals and policies (Appendix E). The focus group reported that DMH provides consumers the same types of services as identified in PC regulations through its residential services. These services include physical assistance with mobility, activities of daily living,

personal hygiene, etc. The focus group identified a significant difference between the DMA PCA program and the PCA-like services provided by DMH. DMH's PCA-like services are provided with a clear goal of rehabilitation, defined as independence from such assistance. The focus group interprets the DMA regulations for PCA to indicate that the consumer's needs are relatively permanent and stable in nature. The group noted that DMH consumers may have permanent needs that fluctuate in nature.

The group estimated that a very small number of DMH consumers may receive DMA funded PCA services. These individuals who are served by both DMH and DMA may be older, or have physical disabilities, or may have organic or neurological disabilities in addition to mental health issues. Individuals with multiple personality disorder or paranoid disorder are thought to possibly qualify for DMA PCA services. However, the focus group estimates that the total number of individuals who might use DMA PCA services in conjunction with DMH services would be approximately 100.

Distribution of Service Hours

The Division of Medical Assistance reports $42.9 million in claims for the PCA program in fiscal year 1994. These claims include PCA, NA, IC, and Holiday PCA rate. With 2688 individuals receiving DMA supported PCA services, the expenditures for PCA support per person are less than $16,000/year. On average, DMA figures indicate the average PCA user claims 39 hours/week of service. Two provider organizations report, on average, 50 hours/week/consumer; a third reports approval for 27 hours/week/consumer but average use at 21 hours/week/consumer.

Data on 498 users of DMA funded PCA services confirm the averages generated from DMA's 1994 figures. The majority of PCA users (n=316) claim less than 55 hours/week of service, and most claim less than 80 hours/week (See Table 1).

Table 1

Distribution of PCA Hours
Excluding Night Attendant

Consumers	Hours
0	<14
66	14 - 29
249	30 - 54
151	55 - 79
20	80 - 104
7	105 - 129
0	130 - 154
5	155 - 168

N=498
(13.5% sample of estimated 3700 PCA user, FY 95)

Requests for Services

Providers report that requests for DMA funded PCA services are denied totally or partially at a rate of 10.3.6% (Table 2). Less than 3% of applicants of this sample are deemed ineligible for PCA; less than 8% are initially determined to have applied for more service hours than they require. Nearly half of the individuals who are denied PCA or who are denied the requested amount of support appeal that decision. One organization reports that 50% of denials are overturned at or before a formal hearing. Anecdotally, one provider reports that families of which the member with a disability is a child are being denied PCA services with less frequency than in previous years.

Table 2

Denial Patterns

	Number	Percent
Requests for PCA	897	
Total Denial	25	2.79%
Partial Denial	68	7.58%
Appeals	46	49.46%
Number Served	872	97.21%

Sample = 4 providers, 897 requests

Comparative Costs of PCA to other Care Models

The Division of Medical Assistance expressed reservations about generalizing costs of PCA services with averages (e.g. average cost per consumer per week or

year). The DMA noted that Personal Care Assistant services are highly individualized and that the ages, types of disabilities, allocations of hours of services of its users vary greatly. DMA was concerned that the use of averages to examine the PCA program would not sufficiently highlight these significant variations. However, data regarding the number of individuals receiving specified ranges of hours of services were not readily available through the DMA. (DMA estimates it would take up to 6 months to calculate how many people receive x hours/week.) Provider organizations did not appear to have the same concerns about generalizability of data and the use of averages to describe program costs. Some provider organizations were able to supply HSRI with average hours allocated per consumer and others reported the distribution of PCA hours (e.g. "26 consumers use between 14 and 29 hours of PCA services per week"). We examine both averages and ranges below. Generally, the differences in hard numbers do not appear substantial.

On average the PCA program administered through the Division of Medical Assistance, costs $44/day. The Massachusetts Rehabilitation Commission's PCA program yields similar costs per day. The MRC PCA program costs $1 million/year; over $200,000 are paid for by the 53 consumers of that program. The MRC PCA program costs $44/day/consumer. Notably, the MRC program is paid for solely with state moneys, whereas the costs of other services and supports in the Commonwealth (including DMA PCA, DMR Home and Community Waiver programs) are shared between Massachusetts and the federal government through Medicaid reimbursement.

When compared to other types of services and support offered by the Commonwealth of Massachusetts, PCA services are significantly less costly (Table 3). Costs of DMA funded PCA and DMR funded services reflect personnel costs only. Administrative, overhead and capital costs are not included in these per diem rates. It cannot be determined whether the nursing home per diem rate reflects personnel costs only, or includes overhead and administrative costs as well. DMH cost data were not available.

Table 3

Costs of PCA and Other Services

PROGRAM	COST PER DAY
DMA PCA	$44
MRC PCA	$43
Nursing Home	$103
ICF/MR	$216
Residential Facility	$145
State-op group residence	$176
Limited group residence	$134
Staffed apartment	$136
Community residence	$71
Satellite residence	$87
Cooperative apartment	$31 *
Specialized Home Care	$38 **

* Generally 15 hours/week of support
** Subsidized family living, 24 hour/day support

Findings

Informants have identified a minimum of 2100 individuals who need, but do not receive PCA or PCA-like services. This estimate includes the 2000 persons with mental retardation who live with their families and the 100 individuals with mental illness who might benefit from the PCA model. This estimate does not include numbers of children with disabilities or older adults whose needs are not being addressed by the PCA program. Therefore, the 2100 identified individuals represents a bare minimum number of the under or unserved population.

Personal Care Attendant services, whether funded by the Division of Medical Assistance or replicated by other state agencies, presents appealing alternative support models for a multitude of people with a variety of needs.

Demand for DMA PCA services by consumers of the Department of Mental Health is likely to be low.

PCA services are less costly than other models of support. PCA costs the Commonwealth less per day per consumer than most other types of assistance offered to people with disabilities. Notably, because PCA is not a facility or program based model of support, overhead costs traditionally associated with such models are not incurred. Further, because users of PCA support are not restricted to receiving support or assistance in specified locations and times, they

may contribute to the tax base through employment and purchasing. The MRC PCA program expects and requires such contributions, and consumers of MRC PCA pay for over 20% of the total costs with direct cash outlays.

Some provider organizations report that the costs of administering the PCA program are not adequately covered by the $0.23/hour of service. One provider notes that the Commonwealth sometimes realizes significant cost savings through the surrogate model of PCA management. In instances where the individual requires significant levels of support, the surrogate may operate as case manager or even provider agency without reimbursement for those management services.

DMA, provider organizations, and individuals are unable to estimate the amount or type of fraud that may occur in the PCA program. All those interviewed believe, however, that fraud is unlikely to occur at the consumer level.

Data regarding the costs of PCA services and the characteristics of PCA users surely exist. However, the accessibility of such data to outside inquiries, as well as DMA staff, is limited. (A contact person at DMA reported that it would take up to 6 months to compile a matrix of the number of individuals by the number of PCA service hours.). DMA must be afforded the resources and support necessary to access and use basic data.

APPENDIX A

Name: _____
Position: _____

Data Guide: PCA Cost Analyses
ILCs & PROVIDERS

1. What are the characteristics of the individuals who use PCA services? Living circumstances, level of disability, multiple disabilities, previous living circumstances, self-direction abilities, age?

2. How many individuals requested PCA this past year? How many received it? What is the average allocation (# of hours/week or month)?

3. How many individuals appealed or challenged a denial of services and on what basis?

4. How many individuals appealed or challenged the level of support as insufficient (when they are approved for PCA services)?

5. What are the average hourly and daily (hourly costs x hours/day/consumer) costs for DMA funded PCA? For other funded PCA?

Name: _____
Position: _____

Data Guide: PCA Cost Analyses
DMR, DMH, & MCB

1. What are the PCA-like services that DMR/DMH provides/funds?

2. What are the characteristics of the individuals who use PCA-like services? Living circumstances, level of disability, multiple disabilities, previous living circumstances, self-direction abilities, ages?

3. How many individuals requested PCA-like support this past year? How many received it? What is the average allocation (# of hours/week or month)?

4. How many individuals appealed or challenged the denial of services?

5. How many individuals appealed or challenged the level of support as insufficient (when they are approved for PCA-like services)?

6. On what criteria does DMR/DMH base approval or rejection for PCA-like services? (e.g. differential diagnoses, age, level of disability, "capped" services, etc.)

7. What is the average daily cost per consumer for:

   Institutional/hospital or ICF/MR care?

Nursing homes?

Group homes?

Staffed apartment?

Cooperative apartment? Semi-independent living?

8. How many individuals are inappropriately placed in various service settings? How many who may succeed with PCA-like support are placed in more restrictive environments? How are these determinations made?

9. What is the average daily or hourly cost for DMR's PCA-like services?

10. What other sources of data and information will be helpful in understanding PCA in the context of this state agency?

Name: _____
Position: _____

DMA & MRC

1. What are the characteristics of the individuals who use PCA services? Living circumstances, level of disability, multiple disabilities, previous living circumstances, self-direction abilities?

2. How many individuals requested PCA this past year? How many received it? What is the average allocation (# of hours/week or month)?

3. How many individuals appealed or challenged a denial of services and on what basis?

4. How many individuals appealed or challenged the level of support as insufficient (when they are approved for PCA services)?

5. On what criteria does DMA/MRC basis approval or rejection for PCA services? (e.g. differential diagnoses, age, level of disability, "capped" services, etc.)

6. What are the average hourly and daily (hourly costs x hours/day/consumer) costs for DMA funded PCA?

7. What is the average daily cost per consumer for:
   Nursing home care?

   In-home nursing/skilled medical care?

APPENDIX B

We wish to thank the following people for the considerable time, effort, and resources expended to supply us with data for this study. Notably:

Larry Tumino, DMR
who performed data analyses and drafted a summary in order to answer inquiries;

Mary Margaret Moore, DMH
who convened and facilitated a focus group of administrators and drafted a report in order to answer inquiries;

Charlie Carr and John Miller, Northeast Independent Living Program
who reviewed individual client data and records to supply accurate information;

Jim Brown, Independence Associates
who reviewed individual client data and records to supply accurate information;

LouAnn Larson, North Shore ARC
who reviewed individual client data and records to supply accurate information.

Additionally, the following people responded to telephone inquiries and supplied data when available:

Jackie Urhig, Center for Living and Working
Kevin Farrell, Director of PCA Program, MRC
Betsy Anne Youngholm, Benefits Services Manager, DMA
Robert Sneirson
Jamie Katz, Heller, Borreliz, & Katz, P.C.
Jim Ross, Community Partnerships
Kim Smith, Rate Setting Commission
Barbara Chandler, Office of Elder Affairs

Appendix C

Massachusetts Department of Public Welfare
600 Washington Street, Boston, MA 02111

P.C.A. BRIEFING PAPER

PERSONAL CARE ATTENDANT PROGRAM

The Medicaid Personal Care Attendant (PCA) program provides personal care services which allow persons with permanent or chronic disabilities, who have an unmet need for assistance with activities of daily living, to live independently in the community instead of being institutionalized. It has never been intended as a day care, companion or baby sitting service, or as a substitute for care provided by parents of minor children or any existing caregiver.

ELIGIBILITY FOR PERSONAL CARE ATTENDANT SERVICES

To be eligible for PCA services, an individual must have a chronic or permanent condition and require physical assistance with activities of daily living as defined in the PCA regulations 106 CMR 422.403.

Consistent with the regulations, Medicaid grants prior approval for payment for PCA services, after an evaluation and review by a registered nurse, for individuals who are determined to have an unmet medical need for physical assistance with activities of daily living.

REVIEW OF PERSONAL CARE ATTENDANT REQUESTS

All prior approval requests for PCA services are reviewed by Medicaid using the criteria listed in the PCA regulations and are approved or denied based on the same criteria. In all instances determination by a nurse is based upon the medical need of the consumer.

Being consistent with federal interpretation, Medicaid considers those individuals receiving personal care from an available caregiver as having no unmet medical need for Medicaid-reimbursed personal care attendant services. However, if as the result of physical limitations, an existing caregiver is, in fact, unable to care for the individual, the inability of the caregiver to provide care for the consumer would be a factor in reviewing the request for services, along with all other medical criteria.

RSONAL CARE ATTENDANT PROGRAM REVIEW

ere has been a significant increase during the last six months in the number
requests for Medicaid-reimbursed PCA services. Medicaid has had to look
refully at all prior approval documentation to ensure that services are being
propriately approved. No regulations have been changed. No services or
ograms have been eliminated.

MMARY

dicaid is committed to the PCA program and to ensuring that those individuals
o are eligible for the program receive the services. When properly utilized,
A service is a cost effective alternative to institutional care.

ESTIMATED COST IMPACT OF EXPANDING THE PCA PROGRAM

The following presents a range of potential new costs which result from expanding the PCA Program by applying a set of criteria and standards different from that stated in the attached program description and different from the original intent of the program regulations originally adopted and subsequently amended in 1988.

Approximately 2,000 clients are currently receiving PCA services reimbursed by Medicaid. The total current annual cost is more than $30 million.

The new cost calculations are based on a number of factors:

1) The hourly rate of $8.09;

2) The average number of hours per week of PCA service used by a client, which we have set at 40 hours, although the average number of hours for our current caseload is approaching 50 and the average request on behalf of applicants who are cognitively impaired appears to be for 45 hours per week;

3) The services will be used for 52 weeks per year on average;

4) The pool of new people potentially requesting PCA services is minimally 15,700 cognitively-impaired or disabled Medicaid-eligible clients (adults and children), as identified by DMR's consumer registry of adults and by DPH's Division of Family Health:

Calculation I (Total of 15,700 clients)

(a)			(b)		
	7700	adults		8000	children
	X$8.09	per hour		$8.09	
$	62,293		$	64,720	
	X 40	hours per week		X 40	
$2,491,720			$2,588,800		
	X 52	weeks		X 52	
$129,569,440			$134,617,600		

The total of (a) and (b) under Calculation I is $264,187,040

5) ...and extends to a much larger pool of about 65,000 clients, Medicaid-eligible, including the cognitively impaired, physically disabled, frail elders, as identified in Frank Bowes' "Disability Demographics in Massachusetts: Implications for MRC", 1987.

Calculation II (Total of 26,729 working adults; 33,879 elders; 5,392 children)

(a) 26,729 Working Adults	(b) 33,879 Frail Elders	(c) 5,392 Kids
X $8.09	$8.09	$8.09
$216,237.61	$274,081.11	$43,621.28
X 40 hours	X 40 hours	X 40 hours
$8,649,504.40	$10,963,244.40	$1,744,851.20
X 52 weeks	X 52 weeks	X 52 weeks
49,774,228.80	$570,088,708.80	$90,732,262.40

a total of (a), (b) and (c) under Calculation II is $1,110,595,200. From this tal, subtract $33,654,400 which represents that cost attributable to the rrent caseload of 2,000. Net total incremental cost resulting from lculation II = $1,076,940,800.

e above calculations do not take into account the additonal evaluations and evaluations which would be involved. This would add another $2 million to million.

Massachusetts Department of Public Welfare
600 Washington Street, Boston, MA 02111

POLICY MEMORANDUM

To: Medicaid Staff

From: Bruce Bullen, Deputy Commissioner for Medical Services

Date: August 31, 1992

Re: INTERPRETIVE GUIDELINES - REGULATIONS GOVERNING PERSONAL CARE ATTENDANT (PCA) SERVICES

The purpose of this memorandum is to provide formal guidelines to assist the Department's staff in interpreting the Department's regulations governing the authorization of Medicaid reimbursement for personal care services provided by a paid personal care attendant (PCA). Specifically, guidelines stated in this memorandum are intended to clarify how Department regulations apply in circumstances where PCA services have been requested either for minor children or for adults with a legal guardian or an existing caregiver.

The regulations governing personal care services provided by a PCA appear at 106 CMR 422.000. These regulations establish that personal care services, which consist of physical assistance with activities of daily living (ADLs), are unskilled. 106 CMR 422.410. ADLs include such activities as bathing, grooming, dressing, toileting, and eating. 106 CMR 422.410(A). Because personal care is unskilled, such activities can be performed by anyone who is able to understand and carry out directions relating to the recipient's personal care needs. 106 CMR 422.404(A). Such activities, therefore, can be performed by a parent, legal guardian, or voluntary caregiver.

In addition to the specific provisions of the PCA regulations, there is the general provision, stated in the Department's administrative regulations, requiring that all services paid for by Medicaid be medically necessary. 106 CMR 450.204. The regulation governing medical necessity establishes a two-part test. That is, the service must 1) have a demonstrable clinical benefit, and 2) be the least costly effective alternative available.

The PCA regulations and the regulation requiring and defining medical necessity should, in all cases, be read together to determine whether personal care services provided by a paid PCA

in a given case are medically necessary and, therefore, reimbursable by Medicaid. Reading these regulations together, personal care services provided by a paid PCA would not be medically necessary where a Medicaid recipient's personal care needs are or can be met by a parent, legal guardian, or existing caregiver. Under such circumstances, even where the clinical test of medical necessity can be met, the "least costly effective alternative" test cannot. Since personal care is unskilled, such care is equally effective in addressing the recipient's personal care needs regardless of whether provided by a parent, legal guardian, voluntary caregiver, or paid PCA. Thus, the personal care of the parent, legal guardian, or voluntary caregiver is a less costly effective alternative to the services of a paid PCA.

Paid PCA services requested for the apparent or express purpose of assisting the parent or legal guardian are not reimbursable under Medicaid. Under such circumstances, the requested service is intended to meet the social need of the caregiver for relief or support, and not the clinical need of the recipient. The Department's regulations expressly prohibit Medicaid reimbursement for services which fulfill a social need. 106 CMR 22.413(A). The Medicaid program is intended to provide medically necessary services to Medicaid recipients. 42 USC 1396. It is not intended to afford to parents or legal guardians the option to choose between providing care themselves, however burdensome, or having an unskilled worker provide essentially the same care at public expense.

I hope this assists you in analyzing policy issues and prior authorization requests relating to PCA services.

K/sd:policy.PCA

c: Roland Cassavant, Director
Division of Hearings

Appendix D

PCA Cost Analysis

Name: Larry Tummino - DMR Assistant Deputy Commissioner

1. DMR provides direct and instrumental A.D.L. support as described in the P.C.A. regulations principally through it's community based residential service system. Generally direct service staff provide this support on a regularly scheduled basis through either a provider agency contract held with D.M.R. or through state employment in the state operated residences.

2. Characteristics of those served in P.C.A. like:

   For purposes of this survey I have included approximate number of consumers who would meet the threshold for P.C.A. services as defined by Medicaid regulation. I included those whose cognitive impairment is considered to be severe or profound mental retardation. In addition, I included consumers with moderate and mild mental retardation who have severe mobility impairments. Very few of those served by the Department can self-direct the P.C.A. supports and must rely on a surrogate. 60% of those receiving P.C.A. like services previously resided in a state facility, 35% lived at home with family, and 5% lived in nursing homes.

3. Number of individuals receiving P.C.A. like supports this past year: 2,736 (Using criteria in #2)

   Number of individuals who requested but did not receive P.C.A. like supports this year: 925 (Using criteria in #2)

   Average allocation of hours/week: 125
   (which includes all overnight hours)

4. Number of individuals appealed or challenged the denial of services: 0 . DMR residential services are provided within available resources and is not an entitlement service.

5. N/A (see number 4)

6. Criteria for approval to receive P.C.A. like services:

   Entry to DMR residential services is based on priority of need when openings arise or new funds are made available for expansion. Priority I are those individuals facing an immediate health and safety risk. Priority II are those individuals whose current circumstances are not adequate. Priority III are those individuals whose services are not appropriate. Priority IV are those individuals whose services are not the least restrictive feasible alternative. Priority V are those individuals for whom alternative services would be desirable.
   For the most part individuals who receive residential services

are in priority I, or II circumstances.

7. *Average Daily Costs - DMR Residential services:

DMA PCA
MRC PCA

	Per Diem Rate
Institutional I.C.F. M.R.	$216
Residential Facility (766 schools)	$145
State Operated Group Residence	$176
Limited Group Residence	$134
Staffed Apartments	$136
Community Residence	$71
Satellite Residential	$87
Cooperative Apartment	$31
Specialized Home Care	$38

NH

Notes -
Institutions = State Schools
Residential Facilities = people who have turned 22 who still reside in 766 approved schools
State Operated Group Residence = staffed with state employees (24 hour staff)
Limited Group Residence - 5 to 8 consumers in specially built accessible housing (24 hour staff)
Staffed Apartments = 2 to 4 consumers in (24 hour staff)
Community Residence - 5 to 8 consumers (24 hour staff)
Satellite Residence = Network of residential support services with a mix of 24 hour and non 24 hour supports
Cooperative Apartments - Routine support less than 24 hours per day. Generally 15 hours a week.
Specialized Home Care - subsidized family living situations (24 hour supports)

*The average daily rates are inclusive only of <u>personnel</u> costs including wages fringe and payroll taxes and <u>excludes</u> other administrative and support costs.

Nursing Homes - Funded by Medicaid

8. Number of individuals inappropriately placed:
-1,200 in Nursing Homes as determined by PASSAR Reviews.
-1,900 in state schools as determined by ISP's

9. Average daily P.C.A. like cost across all residential services adjusted to personnel expense is $107.40 per day.

10. There are currently 450 DMR consumers receiving P.C.A. supports in a variety of settings, including those who are getting supplemental support in residential programs as a means to avoid nursing home placements. Apart from that group, our biggest need is for P.C.A. supports for individuals living with families. Medicaid feels this is a DMR "respite care" issue and that P.C.A.'s can only be provided when primary care givers are physically unable to provide care. This issue is in need of resolution. Given the P.C.A. criteria, it is our estimate that approximately 2,000 consumers could benefit from in-home P.C.A. supports.
It is important to note that the cost of the P.C.A. - like services are reimbursable under Title 19 (facilities) or the Home and Community Based Waiver (community programs)

Appendix E

The Commonwealth of Massachusetts
Executive Office of Health and Human Services
Department of Mental Health
25 Staniford Street
Boston, Massachusetts 02114-2575

William F. Weld
Governor

rgeo Paul Cellucci
Lieutenant Governor

Gerald Whitburn
Secretary

Eileen Elias
Commissioner

Area Code (617)
727-5500
TTY 727-9842

September 21, 1995

Julie Silver
HSRI
2336 Mass. Ave.
Cambridge, Ma 02138

Dear Julie:

Attached for your inclusion in data analysis for the Developmental Disability Council concerning PCA services is the DMH data. As I shared with you, I scheduled a focus group at which five of our seven areas had representatives. The focus group met on September 7, 1995.

The overriding theme of our discussion was that currently DMH provides to DMH consumers the same types of services as identified in the PCA regulations such as assistance with mobility issues, physical assistance if needed with medications, physical assistance with bathing or grooming, dressing, eating, meal preparation and clean-up, and toileting, when necessary. These services are part of the residential assistance provided in our residential programs. Assistance with household services and transportation to medical providers and other providers and assistance with special needs is also provided by DMH to DMH consumers by inpatient staff of state operated and private inpatient services, residential providers, clubhouses, other community provider staff and at times case managers.

The difference, a significance difference, is that our PCA-like services are provided with **rehabilitation** as the focus. Our interpretation of the DMA PCA services is that they are for consistent and permanent needs of a stable nature. The DMH consumer population may have permanent needs for PCA services but it may also be of a fluctuating nature. Our rehabilitation approach is based upon attainment of independence from this assistance as the goal.

A second theme that emerged from our focus group was that we believe that currently the number of DMH consumers who have DMA PCA services is very small. Although we do not know that number we assume that those who are DMA PCA service recipients as well as DMH consumers are those who fall into the following categories:
older consumers and/or
physical handicaps and/or
organically/neurologically disabled.
We believe that there might also be some consumers who have multiple personality disorder or paranoid disorder that might qualify for DMA PCA services. The total number would be small, we estimate perhaps 100, who are using DMA PCA services. We will attempt to educate our

areas and service providers of this service by developing a flyer for distribution in the near future.

If you have further questions, please contact me at 1-617-727-5500, ext.419.

Yours truly,

Mary Margaret Moore

cc: Walter Jabzanka

Data Guide: PCA Cost Analyses DMH
Completed by Mary Margaret Moore, Director, Office of Client Services & Emergency Management

1. What are the PCA-like services that DMH provides?
All of the DMA PCA services listed may at times be provided to DMH consumers within a rehabilitation model. The DMH PCA-like assistance is provided with the goal of independence from such assistance ever present. These services are provided by state operated and provider inpatient staff, as well as provider clubhouse, residential staff and community support workers and at times case managers. The consistent need for physical assistance is only present in a small percentage of DMH consumers.

2. What are the characteristics of the individuals who use PCA-like services?
The characteristics seem to be any of DMH consumers at any time might need physical assistance with medications, bathing, grooming, dressing, eating, meal preparation, and clean-up, toileting, household services, transportation and special needs. Some, a few number, might need assistance with mobility , and range-of-motion exercises. Most would need physical assistance for a limited time period as our expectation is that through rehabilitation the consumer would achieve independence from physical assistance. Yet sometimes the cyclical course of the mental illness may result in consumers needing physical assistance repeatedly. This does not seem be able acceptable to DMA criteria at present for PCA services.

Some consumers, those who have needs for physical assistance with activities of daily living in addition to a major, persistent, chronic mental illness, may need DMA PCA services consistently. Currently if there is a medical need for assistance most DMH consumers receive those services from VNA chapters, home health agencies and this is paid for by medicare or medicaid.
Those consumers who would possibly qualify for DMA PCA services might be older consumers and/ or consumers who have physical handicaps and/or consumers who have organic/neurological impairments. Some consumers who have multiple personality disorder or paranoid disorder might also qualify for DMA PCA services since their needs for physical assistance with activities of daily living may be acceptable to DMA as being permanent or chronic in nature.

3. How many individuals requested PCA-like support this past year? How many received it? What is the average allocation (# of hours/week or month)?

No requests are made for PCA-like services in the normal course of DMH activity. CCSS planning, the DMH local planning process, has indicated unmet needs for services of this type, especially transportation, but the services are not requested directly by the DMH consumer. We are aware that in the Northeast area that 5 consumers who are case managed by DMH are receiving DMA PCA services.

4. How many individuals appealed or challenged the denial of services?

Unknown.

5. How many individuals appealed or challenged the level of support as insufficient when they are approved for PCA-like services?

N/A

6. On what criteria doses DMH base approval or rejection for PCA-like services?

DMH services are individually based. A consumers needs drives the service provision. If a consumer needed PCA-like services DMH would provide or arrange for those services depending upon resource availability.

7. What is the average daily cost per consumer for:
   Institutional/hospital care?

   Nursing homes?

   Group homes?

   Staffed apartments?

   Cooperative apartments/Semi-independent living?

Within the DMH privatized service system costs vary Area system by Area system for all services. Residential costs are at times a combination of multiple funding including DMH, rental assistance, consumer contributions, as well as Medicaid/Medicare. Rental costs vary throughout the state as well as staff costs. Housing costs and services costs are also factors. To determine costs by the above categories is not possible with the question as is.

8. How many individuals are inappropriately placed in various service settings? How many who may succeed with PCA - like support are placed in more restrictive environments? How are these determinations made?

It is not the policy of DMH to place persons in settings which are more restrictive than they require. DMH has made many changes over the past years to move consumers from restrictive settings, usually inpatient settings, to community settings which are as least restrictive s possible. Currently DMH is instituting residential services which can be flexible in terms of support to address the changing needs of the consumer within a rehabilitation approach.

Unlike DMH PCA-like services, the DMA PCA program has not been utilized as a means to assist DMH consumers to move to less restrictive environments but to assist them in whatever settings they occupy. No estimates are available about the impact on level of restriction resultant from utilizing the DMA PCA program by DMH consumers.

9. What is the average daily or hourly cost for DMH's PCA-like services?
There are a variety of providers, staff, and shifting consumer needs for PCA-like services as described above and thus there is no average daily or hourly cost that we could derive at this time. Staff at numerous sites may be providing some PCA-like services at times, such as clubhouse staff providing transportation to consumers, or family assisting with personal care needs.

10. What other sources of data and information will be helpful in understanding PCA in the context of DMH?
Consumers of DMH who apply for DMA PCA services have reported that the process is difficult. They and many mental health professionals do not understand the DMA PCA application process not do they understand the criteria. For the few who have received DMA PCA services there is a problem with the two month delay in payment of PCA's. For a consumer with no complicating medical condition who needs a PCA strictly for a psychiatric condition the qualification process is currently very difficult, although not impossible.